

# Report on NCI Extramural Cancer Epidemiology Cohort Studies

Julie R. Palmer, ScD and Leslie L. Robison, PhD  
for the *Ad Hoc* Working Group on Strategic Approaches and Opportunities  
in Population Science, Epidemiology, and Disparities

**Meeting of the *Ad Hoc* Subcommittee on Population Science,  
Epidemiology, and Disparities  
NATIONAL CANCER ADVISORY BOARD  
June 9, 2019**

# Working Group Members

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Boston University

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Albert Einstein College of Medicine

St. Jude Children's Research Hospital

Baylor College of Medicine

Emory University

National Cancer Institute

# Initial Charge to the Working Group from Dr. Sharpless

Assist the Subcommittee by engaging in discussions and developing recommendations on four focus points:

- Near-term concerns and long-term goals for existing and future cohort studies
- Better use of cooperative groups to address disparities
- Survivors and cancer survivorship
- Extramural training programs for scientists in population sciences, epidemiology, and disparities

Dr. Sharpless suggested beginning with the first two focus points

Charge given to the Working Group at first telephone meeting, June 19, 2018

# Timeline of Working Group Activities

**Invitations to Working Grp.**

**Sharpless - Charge to Working Grp.**

May June July Aug Sept Oct Nov Dec Jan Feb Mar Apr May June

2018 2019



A timeline diagram showing a sequence of events from May 2018 to June 2019. A dark grey line slopes downwards from left to right. A light blue dot is placed on the line at the July 2018 mark. Two text boxes are connected to the line: a dark blue box labeled 'Invitations to Working Grp.' is connected to the line at the June 2018 mark, and a light grey box labeled 'Sharpless - Charge to Working Grp.' is connected to the line at the July 2018 mark. The timeline is labeled with months from May to June for the years 2018 and 2019.

# Timeline of Working Group Activities

**Invitations to Working Grp.**

**Sharpless - Charge to Working Grp.**



A timeline diagram showing a sequence of events from May 2018 to June 2019. A diagonal line descends from the top left to the bottom right. A light blue dot is on the line at July 2018, with a callout box 'Invitations to Working Grp.' pointing to it. A light grey dot is on the line at August 2018, with a callout box 'Sharpless - Charge to Working Grp.' pointing to it. There are seven dark blue dots on the line, one for each month from September 2018 to May 2019. The timeline ends at June 2019.

Month	Year
May	2018
June	2018
July	2018
Aug	2018
Sept	2018
Oct	2018
Nov	2018
Dec	2018
Jan	2019
Feb	2019
Mar	2019
Apr	2019
May	2019
June	2019

## Initial phone calls

- Clarification of scope of the charge  
Narrowed to a focus on cohort studies:  
“near-term concerns and long-term goals  
of existing and future cohorts”
- Defining the key questions under that theme
- Developing a process for addressing the questions and coming up with a report
- Information gathering

# Timeline of Working Group Activities

Invitations to Working Grp.

Sharpless - Charge to Working Grp.

*All of US* COHORT

SEER

DCEG CONNECT COHORT

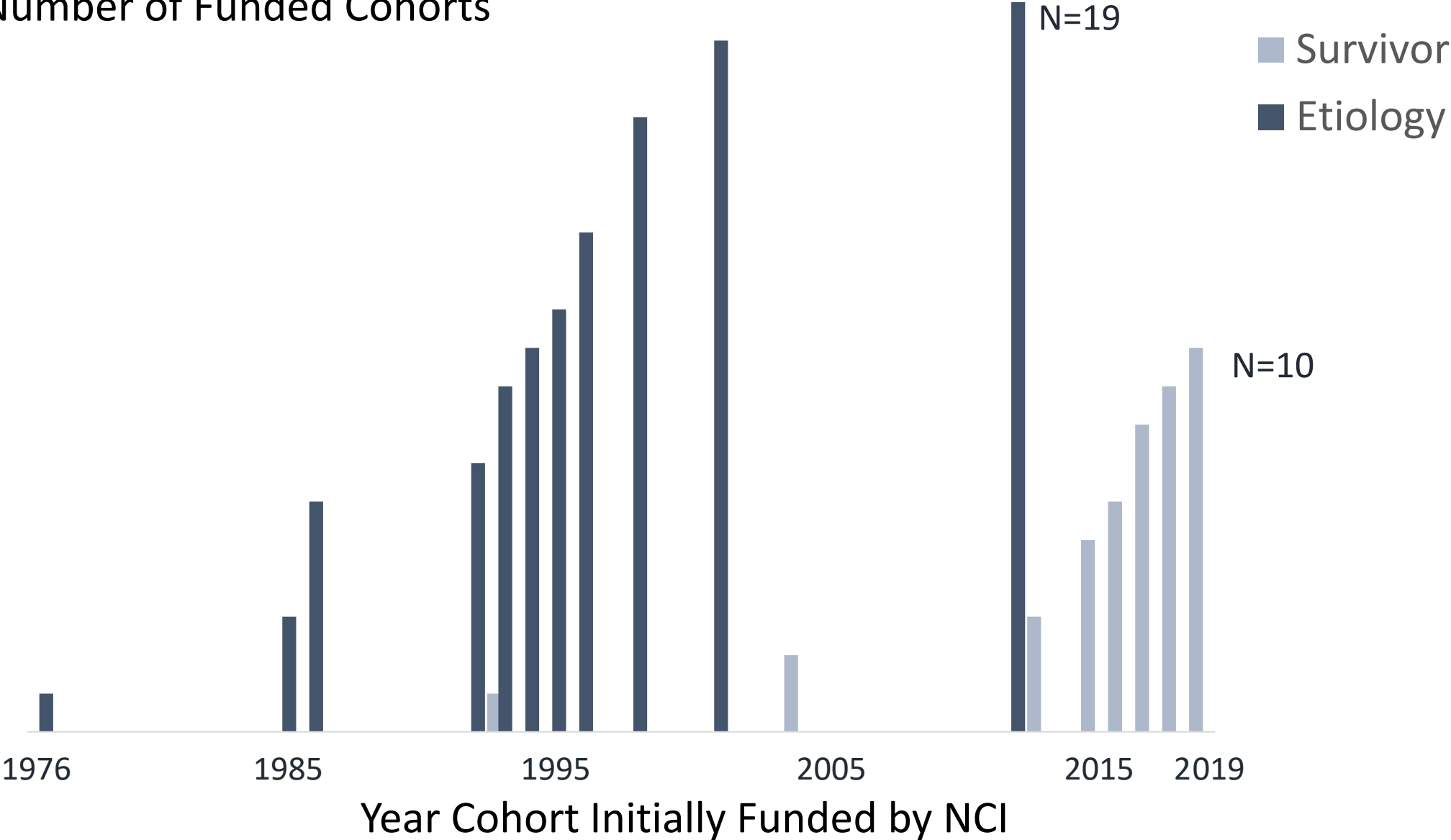
NCI COHORT EVAL. PROJECT

VIRTUAL POOLED REGISTRY

May June July Aug Sept Oct Nov Dec Jan Feb Mar Apr May June  
2018 2019

# NCI Current Portfolio

Cumulative Number of Funded Cohorts

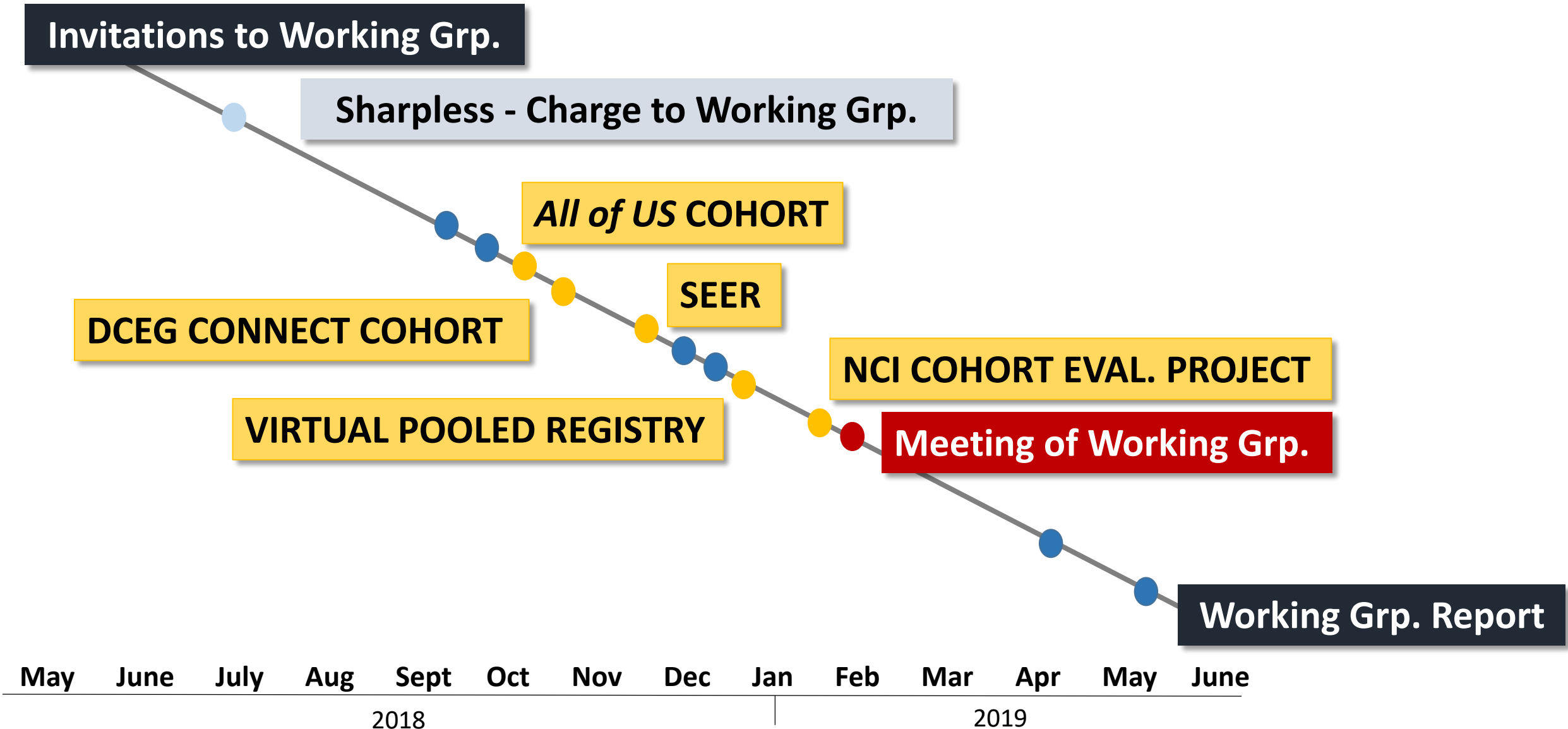




## Preparations for 2-day meeting at NCI in January

- Assign 1-2 WG members to each question
- Subgroup phone calls
- Prepare slide set for each question (N=6)

# Timeline of Working Group Activities



## **Question 1. The role of cohort studies in etiologic and survivorship research in human populations**

How can NCI ensure that its cancer epidemiology cohort portfolio has the potential to address future questions related to cancer risk, cancer recurrence, cancer survival, and cancer-related long-term health outcomes?

## **Question 1. The role of cohort studies in etiologic and survivorship research in human populations**

How can NCI ensure that its cancer epidemiology cohort portfolio has the potential to address future questions related to cancer risk, cancer recurrence, cancer survival, and cancer-related long-term health outcomes?

## **Question 2. Utility of cohorts for addressing cancer health disparities**

What is the best way to ensure that the portfolio includes cohorts with large numbers of one or more populations that have been understudied and underserved?

### **Question 3. Study design considerations for extramural cancer epidemiology risk and survivor cohorts**

What are the optimal study designs to address cancer risk, recurrence, survival, and long-term health-related outcomes following cancer in human populations?

## **Question 4. Data sharing and collaboration**

How can NCI ensure that the extramural scientists responsible for designing, organizing, and maintaining the cancer epidemiology cohorts remain motivated to continue these time-consuming efforts in this era of rapid sharing of data?

## **Question 5. Funding models for cohorts**

Is the funding mechanism to support cancer epidemiology cohorts optimal? If not, what other models might be better?



# Working Group Report

Executive Summary

Overview of observational cohorts in the NCI Extramural Portfolio

Five specific questions

- Background

- Working Group assessment

- Recommendations

# Selected Recommendations and Opportunities for Enhancement

## Q1. The role of cohort studies in etiologic and survivorship research in human populations

.... there are circumstances where a cohort design reflects the most scientifically rigorous approach..... to investigate important existing and emerging topics relating to cancer risk and outcomes.

Thus, NCI should invest in providing sufficient infrastructure support for cohorts to.... address critical scientific gaps, anticipate the scientific questions of the future, and considers societal issues that are deemed to be of high importance with high impact.

# Selected Recommendations and Opportunities for Enhancement

## Q1. The role of cohort studies in etiologic and survivorship research in human populations

.... continue to support new and existing focused cohort studies to address specific cancer etiology and survivorship questions...

.... promote and facilitate the use of existing and planned intramural cohorts in order to leverage access of these resources for the broader extramural community....

.... support establishment/expansion of national infrastructure for ascertainment and follow-up of cancer cases....

# Selected Recommendations and Opportunities for Enhancement

## Q1. The role of cohort studies in etiologic and survivorship research in human populations

.... use of prevention and cancer therapy trials to address etiological research.... new survivor cohorts, opportunities to leverage the patient populations available through the NCI-supported cooperative clinical trials groups and the NCORP...

.. support the conduct of pilot studies to determine the feasibility and design for establishing an adult survivor cohort to investigate treatment-related adverse outcomes....

.... opportunities to draw upon the strengths/attributes of cohorts to conduct intervention research....

# Selected Recommendations and Opportunities for Enhancement

## Q2. Utility of cohorts for addressing cancer health disparities

.... additional cohorts are required to fill existing and future gaps in the NCI cohort portfolio.... on underrepresented populations.... insufficient numbers across the portfolio to allow meaningful within-group comparisons.

.... support additional biospecimen collection in existing cohorts that have an appreciable number of participants from a single underrepresented group to address scientifically important questions.

# Selected Recommendations and Opportunities for Enhancement

## Q3. Study design considerations for cancer epidemiology risk survivor cohorts

- .... identify possible opportunities for embedding cohorts in interventions trials for primary prevention, screening and treatment ....
- .... when scientifically justified, incorporation of serial data and biospecimen collection over time to capture time-dependent events...
- .... support and facilitate methodological research to identify efficient and effective approaches for longitudinal specimen and data collection.

# Selected Recommendations and Opportunities for Enhancement

## Q4. Data sharing and collaboration

.... Guidelines and/or mandates for data sharing of cohort-based data must take into consideration the investment of time and academic implications for investigators establishing and maintaining the cohort....

.... The investigator and staff time/effort associated with data sharing/collaborative efforts... ongoing funding for data sharing will be needed... supplements have not been an appropriate funding approach because of the limited timeline for activities.

# Selected Recommendations and Opportunities for Enhancement

## Q4. Data sharing and collaboration

.... for existing cohorts... informed consents may not allow some types of data sharing... may not always be feasible to re-consent participants...

.... new cohorts should consent for broad data sharing as part of the initial enrollment procedure.



# Selected Recommendations and Opportunities for Enhancement

## Q5. Funding models for cohorts

.... NCI should continue to use a Cohort Infrastructure Program Announcement for funding of infrastructure... Investigator-initiated hypothesis-driven research based on cohorts should be funded through R grants, P01s and related mechanisms.

.... It may be most effective for NCI to accept applications for new cohorts only in response to a call for applications, which would occur periodically as needed... applications for new cohorts should be considered in a special study section, separate from reviews of continuations of cohort.

# Selected Recommendations and Opportunities for Enhancement

## Q5. Funding models for cohorts

.... Decisions about when to stop funding active follow-up of a given cohort should be based upon peer-review and the likely future productivity and importance of future findings...

Questions and Comments